Name of the study: Research Ethics: Towards the Development of Professional Principles and Guidelines for Conducting Research among Individuals with Intellectual Developmental Disabilities (IDD)

- ⚙ **Year:** 2023
- ⚙ **Type of research:** Research
- ⚙ **Catalog Number:** 890-182-2019
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Abstract

Professional principles and guidelines for conducting research among individuals with intellectual and developmental disabilities (IDD) have not been sufficiently developed. For example, there is a lack of clarity regarding the process of informed consent and the meaning of guardianship, offending the sensitivities of individuals with IDD, their exclusion from research due to the bureaucratic difficulties involved in including them and the financial cost involved, unjustified overprotectiveness, and exploiting individuals with IDD. Therefore, the current study, which exposes the specific dilemmas, challenges, and principles involved in performing research on individuals with intellectual and developmental disabilities while taking into account the Israeli context.

The main research goal is to raise and examine ethical dilemmas and principles related to conducting research among individuals with IDD. This goal will help formulate a document on professional principles and guidelines on research among individuals with IDD, with an emphasis on the Israeli context. This document is intended for all those who have some stake in conducting research among individuals with IDD, so that they will be aware of what is appropriate and what is prohibited in research involving individuals with intellectual and developmental disabilities (IDD).

The data processing method was based on two stages: In the first stage, the study analyzed some 20 documents of principles from organizations that are authorities in this field, recommended by researchers and members of ethics committees (for example, departments of various universities around the world, hospitals, non-profit associations, recognized organizations – GCP, CITI, NIH), which address principles and guidelines for conducting research among individuals with IDD. In addition, a previous study on ethics in research involving individuals with IDD by Michlol, the Shalem Foundation's assessment and measurement unit, was also utilized. From these documents we extracted ethical dilemmas and

principles related to the study of individuals with IDD. Then, with the support of the steering committee following the study, which included representatives from the Ministry of Welfare and Social Affairs and from the Shalem Foundation, referred the researchers to potential participants, whom the researchers contacted in request that they participate in the study.

In the second stage, those who consented to participate were divided into seven research groups: policymakers, non-profit organizations and employers in the free market, researchers at varied academic institutions, members of ethics committees, professionals and practitioners in the field, guardians and decision supporters, and individuals with IDD. The number of participants in each research group ranged from 8-14. The participants raised ethical issues, professional principles, and derived guidelines for conducting research among individuals with IDD. In this way, the main dimensions of ethical dilemmas and professional principles that derive from different points of view were raised, which reduced the potential of a research bias due to reporting by a single source (i.e., by only one of the groups).

After extracting the principles from the documents in the first stage, the interviews were analyzed in the second stage using qualitative methodology (Williams & Moser, 2019). The research findings indicated that most of the ethical dilemmas (open coding) were common to the different research groups and related to four topics that constitute main axes (axial coding): (1) Involvement of team members in the study versus research reliability, (2) Prior familiarity with IDD populations versus familiarization in the course of the study, (3) Protecting the well-being of respondents with IDD versus maintaining their privacy and including them in research, (4) Professional adaptation of the research tools and increasing their accessibility versus utilizing the researcher's general knowledge.

The four ethical dilemmas generated four ethical principles that were shared by all the research groups and that involve adapting work rules to the needs and features of individuals with IDD, the principle of preventing and minimizing damage, the importance of including individuals with IDD in research, and the principle of protection.

In addition, specific ethical principles unique to the different research groups were also found. For example, among the group of policymakers developing and promoting policy and legislation to deal with ethical dilemmas in research was found to be important. Another unique principle was found in the group of professionals and practitioners in the field and in the group of guardians and decision supporters, regarding the need to utilize persuasion and publicity so that guardians in different roles (parents, social workers) will approve the inclusion of individuals with IDD in research. Aside from the unique principles found, there are subcategories on which differences of opinion were found in the various groups. Thus, with regard to the researcher's experience and knowledge, there is a lack of agreement regarding the researcher's ability to investigate the IDD population with no prior knowledge of their characteristics. Moreover, the

involvement of team members was found to be an issue for discussion among the various research groups due to the personal acquaintance of team members who have connections to individuals with IDD, which might affect the reliability of the study and the reliable inclusion of individuals with IDD in the research.

Theoretically, the study raises various ethical challenges and dilemmas involved in including individuals with IDD in research. The importance of this study will be manifested in the development of a theoretical body of knowledge that includes features of the unique dimensions involved in conducted research among individuals with IDD, with reference to the Israeli context. This will help resolve the vagueness surrounding the research focusing on individuals with IDD. This process of clarification will help stakeholders interested in including individuals with IDD in research follow ethical standards, in order to better understand the worldview of individuals with IDD and examine topics that interest them through research. In this way, the research will be expanded to promote their well-being.

From a practical perspective, the research products consist of the development of a document of ethical principles based on the research findings, while presenting the unique ethical dilemmas and main principles involved in conducting research among individuals with IDD. Moreover, this study included the development of a website that notes incidents involved in the research of individuals with IDD and options for dealing with these incidents, based on the principles found in the study. Thus, stakeholders interested in conducting/ facilitating research among this population will be advised to use the website as a tool ensuring that ethical standards for conducting research among individuals with IDD are upheld. The website is accompanied by a guide that includes a summary of the ethical dilemmas and the principles derived from them, as well as appendices such as: suggestions for forms that increase accessibility by using simpler linguistic forms, which relate to individuals with IDD on different levels of functioning; and a suggestion for a designated consent form for guardians. It is becoming apparent that the website might provide a response for research among an array of individuals with disabilities and not only among those with IDD.

Keywords: intellectual developmental disability, research ethics, ethical dilemmas, challenges, principles, guardians, decision supporters, ethics committees, employers in the free market, non-profit organizations, social workers, policymakers, linguistic simplification and accessibility, informed consent, exclusion.

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